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Electronic Health Information Exchange Opportunities for Self-management of Care: Responses from Older Adults With and Without Cancer History in the United States

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Abstract

Purpose of Study—Of 15.5 million US cancer survivors, 80% are ≥ 55 years. Supporting older patients in care self-management through electronic health information (EHI) exchange may enhance recovery. We assessed: (1) perceived importance of EHI access to adults ≥ 55 years (incl survivors) and (2) age-related preferences for EHI exchange.

Recent Findings—Older adults are one of the fastest-growing user groups for internet/technologies. Most older adults 55–64 years are active internet users, and use among adults ≥ 65 years is growing quickly as baby boomers mature. Understanding EHI patient-provider exchange preferences may provide opportunities for older patients but also begin to address the future needs of other patient populations, including cancer survivors.

Summary—We observed a “digital divide” for perceived importance of EHI access and EHI exchange interests. Engaging older adults (i.e., ≥ 75 years) to improve comfort/experience with technologies may support EHI use in self-management. Survivors may have distinct EHI needs/preferences than older adults without cancer history.

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Compliance with Ethical Standards

Conflict of Interest: Shirley M. Bluethmann, Kisha I. Coa, Catherine M. Alfano, and Bradford W. Hesse declare they have no conflict of interest.

Human and Animal Rights and Informed Consent: This article does not contain any studies with human or animal subjects performed by any of the authors.

Keywords

Cancer informatics; Self-management; Health information technology; Healthy aging

Introduction

There are > 15 million US cancer survivors (i.e., individuals who have been diagnosed with one or more cancers), more than 80% of whom are ≥ 55 years [1]. Of these survivors, 67% have lived 5 years or more after initial diagnosis [2], which presents major challenges for the scientific and medical community [3]. The first challenge is how to serve the needs of an older cancer population, including effective strategies for health promotion and survivorship care. A further challenge is trying to match the finite capacity of the provider community with a growing population of survivors, which is projected to reach 26 million by 2040 [4•].

One way to address these challenges is to equip survivors with tools to manage their own healthcare needs, a growing area of research known as care self-management [5]. Self-management has been highlighted as a pivotal way to improve access and quality of care for many patients [6]. Electronic health information (EHI) exchange, using internet or other mobile technologies to access, report or seek health advice electronically, is one strategy proposed to support self-management in survivors and other older adults [7, 8]. Although older adults' technology use is often framed as an example of an age-related disparity, or "digital divide" [9–12], older adults are now one of the fastest-growing user groups for the internet and other technologies [13]. The Pew Internet and American Life Study found that 65% of older adults 55–64 years were active internet users [14], and that the proportion of internet users among adults ≥ 65 years will grow quickly as tech-savvy baby boomers mature. Promoting EHI exchange between providers and patients, then, may provide opportunities to educate and communicate with older patients but also begin to address the future needs of specific patient populations, including survivors [15].

Previous studies have identified distinct and diverse EHI needs of survivors [16–18], but others have emphasized persistent, unresolved technology barriers (such as low access and insufficient training) among older populations, that may intensify during cancer recovery [11, 13]. Further, preliminary research suggests that older adults, who frequently experience multi-morbidity, may desire guidance in using technology for self-management and self-advocacy in managing complex health needs [19]. EHI use may promote health and reduce risk of behaviors associated with chronic disease burden [20], and support a broader agenda in optimizing aging through technology [21].

To assess the potential for EHI-based interventions for older survivors/older adults, we still to understand more about preferences and optimal EHI uses in patient engagement. Our study's purpose was to (1) assess the perceived importance of EHI access to older adults with/without cancer history and (2) to articulate specific preferences for EHI exchange with providers among these groups. Recognizing the heterogeneity of the needs and preferences of adults ≥ 55 years [22, 23], we also compared responses across age-related subgroups of older adults.

Methods

We used the Health Information National Trends Survey (HINTS) 4, a nationally representative, cross-sectional survey of US adults, which collects data on technology, health-related knowledge, and behaviors. All cycles of HINTS 4 data were collected by mail mode. Following are response rates for HINTS 4 iterations: HINTS 4 Cycle 1 (2011) [37%], HINTS 4 Cycle 2 (2012) [40%], and HINTS 4 Cycle 3 (2013) [35%], and HINTS 4 Cycle 4 (2014) [34%]. We merged datasets following procedures recommended in the HINTS methodology report [24], including applying survey weights to support interpretation of data as nationally representative. Additional information about data collection for HINTS 4 is described in detail elsewhere [25]. For this study, we used available data collected 2011–2014 from all four cycles of survey administration.

Measures

Perceived importance of EHI access was assessed in all cycles of HINTS 4 by asking, “How important is it to you to be able to get to your own medical information electronically?” Based on initial data exploration that revealed a trend toward extreme responses (i.e., most replied “very interested” or “not at all interested” for every option), this variable was dichotomized. Individuals who responded “very important” or “somewhat important” were categorized as perceiving EHI access as “important” and those who responded “not at all important” were categorized as perceiving EHI access as “not important.”

Interest in preferences for EHI exchange with providers was assessed by asking “How interested are you in exchanging the following types of medical information with a health care provider electronically?” in HINTS 4, Cycle 3. There were nine options for EHI exchange with providers: appointment reminders, general health tips, medication reminders, lab/test results, diagnostic information (e.g., medical illnesses or diseases), vital signs (e.g., heart rate, blood pressure), lifestyle behaviors (e.g., physical activity, food intake), symptoms (e.g., nausea, pain), and digital images/video (e.g., photos of skin lesions). As before, we observed extreme responses (mostly “very interested” or “not at all interested”), and so these responses were also dichotomized. Individuals who responded “very interested” or “somewhat interested” in each option for EHI exchange were categorized as interested, and individuals who responded “not at all” or “a little interested” were categorized as not interested.

Covariates

We included gender, race/ethnicity (non-Hispanic white, non-Hispanic Black/African-American, Hispanic, and other), age (< 55 years, 55–64 years, 65–74, 75 + years), general/perceived health status (excellent/very good, good/fair, poor), education (less than high school, completed high school, some college, college graduate or more), marital status (married/living as married, single/separated), smoking status (daily smoker, occasional smoker, never smoked), internet user (yes/no), and cancer history (ever diagnosed with cancer). Because several variables had multiple categories, a preliminary comparison was conducted with ANOVA testing to assess appropriateness of combining these. Non-

significant differences between groups supported the creation of combined categories for several predictors (i.e., age, race/ethnicity, marital status, education, and general health).

Analysis

Analyses were conducted using STATA version 13 (StataCorp, College Station, Texas) and weighted to account for the complex sampling design. Descriptive statistics were used to summarize the study population by demographic and clinical characteristics (Table 1). Multivariable logistic regression was used to assess perceived importance of EHI access, as predicted by demographic characteristics and other covariates. Using a backwards stepwise approach, we assessed statistical significance ($p < 0.05$), and dropped non-significant variables to improve model fit. However, to retain face validity in considering the needs of older adults, we retained key variables, including gender, education, race, and cancer history, regardless of significance.

To assess overall interest in options for EHI exchange with providers, we first calculated weighted proportions for each option. When exploring aggregated data, we observed strong similarities between age groups, which made specific associations with cancer history difficult to detect. We subsequently stratified by both age group and cancer history to isolate the influence of cancer history on specific preferences of adults by age group. Next, we conducted a proportions test using odds ratios to assess significance of interest in each EHI exchange option among participants. Observing very little variability in interest in any specific option over another, we created a composite variable that combined all nine EHI options into a binary dependent variable (interested v. not interested in 1 option) and conducted logistic regression controlling for covariates. This procedure is similar to a previously published study that used HINTS 4 data [26•].

Given growth of internet use by older adults [14, 27, 28], we focused on internet use in exploring opportunities for EHI exchange and self-management with older patients. Prior internet use was included as a predictor in all models.

Results

We analyzed responses from adults ≥ 55 years ($n = 7129$), including 1586 survivors (excluding non-melanoma cases) (Table 1). The mean age was 69 years, ranging from 55 to 96 years. Most participants were white (61%) and female (57%). Older adults were largely similar in groups with/without cancer history. However, adults without cancer history were slightly younger (mean age 67 years) than survivors (mean age 71 years), who were more evenly distributed by age. Most participants (> 60%) were well educated regardless of cancer history. History of internet use was equivalent between survivors and adults without cancer history, the majority of respondents (> 65%) describing themselves as internet users.

Perceived Importance of Electronic Health Information Access

Most (89%) participants perceived EHI access as important, but in models we noted a linear decline in perceived importance by age-related subgroups (Table 2). Those ages 65–74 were less likely (OR = 0.62, $p < 0.01$) than participants 55–64 years to say EHI access was important, a pattern that persisted in adults ≥ 75 years (OR = 0.34, $p < 0.001$). College-

educated participants (OR = 1.68, $p < 0.05$) were significantly more likely to describe EHI access as important compared to less educated groups. Participants without experience using internet or internet-based e-mail were significantly less likely to perceive EHI access as important (OR = 0.32, $p < 0.001$) compared to internet users.

Demographic factors (e.g., gender, race) as well as health risk factors (i.e., cancer history, general health, and BMI) were not significant predictors of perceived importance of EHI access.

Older Adults' Preferences for EHI Exchange With Providers

The survey offered multiple options to assess interest in EHI exchange with providers, ranging from appointment reminders and general health tips to diagnostic services, such as lab reports and diagnostic images. Overall, interest in all options was modest (Fig. 1). In descriptive analysis, the option for appointment reminders was most popular, especially among adults 55–64 and 65–74 years, irrespective of cancer history. Approximately 80% of adults 55–74 years expressed interest in this option. Lifestyle advice and symptom reporting options were less popular, especially among survivors.

Less than half of survivors (42%) and all adults without cancer history (38%) were interested in using EHI with providers for lifestyle advice. Similarly, roughly half of survivors (46%) and other adults (42%) were interested in sharing information about symptoms with their providers electronically.

In almost every option, a higher proportion of adults 55–64 and 65–74 years were interested in EHI exchange with providers compared to adults ≥ 75 years, regardless of cancer history. For example, 60–70% of all adults 55–74 years were interested in medical reminders, sharing information about vital signs and diagnostic information. Most adults ≥ 75 years reported less interest in these options. Less than 30% of adults ≥ 75 years expressed interest in exchanging lifestyle advice or digital images. However, cancer survivors ≥ 75 years were slightly more interested in these options compared to those ≥ 75 years without cancer history. Specifically, > 55% of survivors ≥ 75 years were interested in exchanging lab results electronically compared to 45% of adults ≥ 75 years without cancer history (Fig. 1). In testing proportions for odds of interest in EHI options, we found similar patterns. Among survivors, those ≥ 75 years were less likely to be interested in most EHI exchange options compared to survivors 65–74 and 55–64 years. Adults ≥ 75 years without cancer history were also significantly less likely than adults 65–74 years to be interested in appointment reminders (OR = 0.62, $p < 0.05$), medical reminders (OR = 0.66, $p < 0.05$), and general health advice (OR = 0.61, $p < 0.001$).

We ran a multivariable logistic regression model to assess interest in one or more of the options, controlling for covariates. We observed that less education was generally associated with less interest in any of the EHI exchange options, but these associations were not significant (Table 3). Though membership in racial/ethnic groups was not a significant predictor of perceived importance of EHI access, we did observe strong associations for non-Hispanic (NH) Black and Hispanic adults for interest in any of the options for EHI exchange with providers, independent of cancer history (Table 3). NH Black adults were

51% more likely than NH whites to express interest in any of the EHI exchange options (OR = 1.51, $p < 0.005$). Hispanic adults were also significantly more likely than NH white adults to express interest in any of the EHI exchange options (OR = 1.5, $p < 0.005$). Adults with fair/poor health were also more likely than those with good/excellent health to be interested in EHI exchange with providers (OR = 1.27, $p < 0.10$). Finally, we observed that occasional smokers (OR = 1.29, $p = .07$) and never smokers (OR = 1.54, $p < 0.05$) were more likely than smokers to be interested in any of the options EHI exchange with providers.

Cancer history was not a significant predictor for interest in any of EHI exchange options. However, survivors were slightly more likely than adults without cancer history to be interested in any of these EHI exchange options with providers. As before, internet experience was significantly associated with interest in any EHI exchange option; individuals that did not use the internet were half as likely as internet users to be interested in any of the EHI exchange options (OR = 0.5, $p < 0.001$) (Table 3).

Discussion

Interest in a rapidly evolving selection of EHI tools to assist in better self-management of health conditions, including cancer, has grown since the early days of the HINTS survey. In its earliest administrations, HINTS questions focused on using information from multiple communication channels to support self-management needs and address disparities in information access. As the Internet was one of the newest channels available to survivors at the time, specific questions were included in the survey to assess general information seeking in electronic environments, online medication ordering, and email to communicate with providers [29]. From these early studies, it became apparent that untethered internet use without connection to healthcare systems was perceived as insufficient by patients to meet cancer information needs. Survivors reported lack of confidence in their ability to find answers to questions, especially after primary cancer treatment [30, 31]. With passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 [32], federal policies prioritized “meaningful use” in deployment of health information technology [33]. One core meaningful use criterion was “patient engagement,” operationalized as the ability of patients to view, download, and share personal health information. The new questions added to HINTS 4 were developed to assess interest in these functions.

In the current study, we analyzed data across all four cycles of HINTS 4 to understand, from older adults, the importance of EHI access and to explore interest in using currently available EHI functions. The analyses distinguished between older adults with/without cancer history, which is key in studying this large and heterogeneous population. Reassuringly, the data suggest that most US adults expressed interest in utilizing EHI tools to manage their own conditions. Not surprisingly, this interest was highest among those who reported internet use. Demographic differences parallel previous HINTS studies on use of online technologies, with a strong positive correlation with education (i.e., highly educated groups show greater interest in self-management tools) and an inverse correlation with age (younger groups are more adept with new technologies and thus show more interest in utilizing Health IT tools) [17, 34]. Just as notably, there were no differences detected on

perceived importance of EHI access by gender or race. In fact, there appeared to be greater interest by NH Blacks and Hispanics than by NH whites in using any EHI exchange option. Again, this parallels findings from other studies in which Hispanic and NH Black communities have shown a more rapid adoption of newer technologies, such as social media, than NH white counterparts [35•, 36]. It also provides an opportunity to consider cultural tailoring in the design of online self-management tools for older adults, including survivors, as a way to make self-management tools more relevant and engaging for users.

The study used a large sample of nationally representative data to provide insights on older adults, a growing and vulnerable population. It has specific implications for modern health technology to improve care of older adults, including survivors, which continue to be underserved by current care systems. However, there were limitations. Though large, the analyses used cross-sectional data and do not provide information about causality. Additionally, due to power issues and other considerations, data were pooled, which may increase the risk that data were lost. Only HINTS 4, Cycle 3, asked the question about EHI exchange preferences, so our analyses were limited based on available data. However, all data were compelling and provided similar results to other HINTS reports [26•, 34, 37]. Given survey weighting procedures and large sample size, we believe these results provide an accurate picture of perceived importance of EHI access and potential uses for EHI exchange between older adults and providers. Also, generational effects will undoubtedly influence preferences over time as baby boomers retire and millennials mature. These same questions are planned for inclusion in upcoming administrations of the HINTS 5 Cycles for future longitudinal analyses.

A closer inspection of interest patterns for EHI use—parsed by age groups and survivor status—provides a more nuanced profile across age groups. From these data, interest in clinically relevant EHI uses (e.g., accessing lab results, monitoring vital signs, medical reminders) was especially notable, with survivors showing the greatest interest within the age bracket. Differences between survivors and those without cancer history were not noted within that age group for areas of general relevance (e.g., receiving appointment reminders, accessing general health tips). Interest was generally lower across all dimensions for adults ages 65–74 and lowest in the 75–84 age bracket. Within these age brackets, however, survivors expressed more interest in EHI functionality than those without cancer history. This finding concurs with Pew Foundation data suggesting older adults show greater interest in online self-management tools after being diagnosed with a chronic disease and experience the benefits of managing their conditions firsthand [38]. However, optimal uses for EHI exchange with the oldest users are still unspecified. More research is sorely needed on how to engage the oldest adults (> 75 years) and connect with their values to achieve relevance for this understudied population.

Conclusion

These findings are especially relevant to oncology and primary care practices given the evolving context of cancer care as described by the American Society of Clinical Oncology in its “State of Cancer Care in America, 2017” report [39••]. The report suggests that oncology is necessarily entering a phase in which “real world evidence and data sharing”

will steer the efforts of oncology practices to improve the lives of patients. Data sharing and EHI will be essential for fueling efforts to improve quality of cancer care delivery, for accelerating scientific discovery, and to empower patients who are projected to live longer with the sequelae of their cancer treatments.

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• Of importance

•• Of major importance

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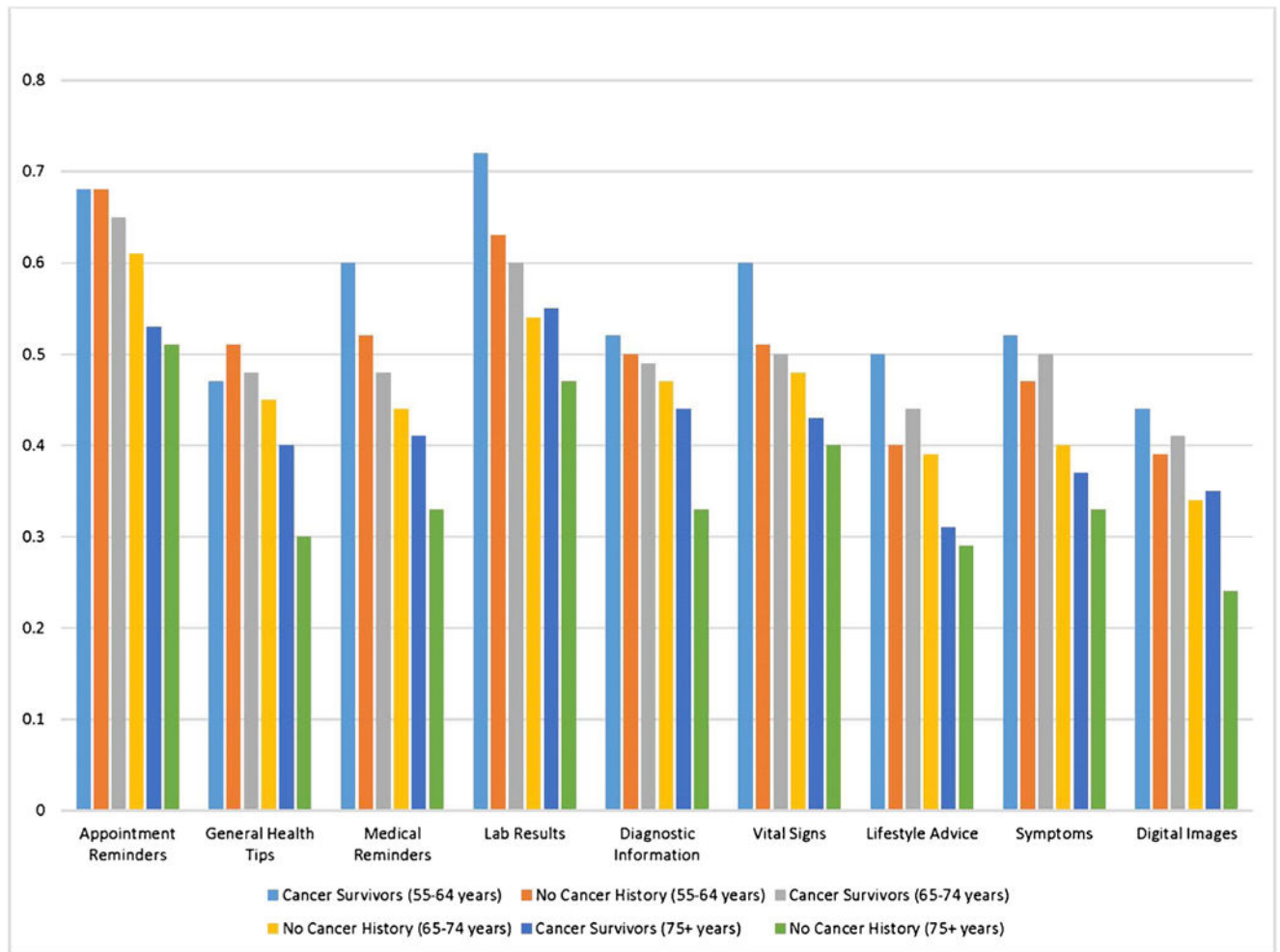


Fig. 1.
Older Adults' preferences for EHI exchange with providers: Weighted proportions by cancer history and age group

Table 1

Weighted characteristics for participants (adults 55 years by cancer history)

Characteristic	Adults 55 (<i>n</i> = 7129)	Older adults with cancer history (<i>n</i> = 1586, 18%)	Older adults without cancer history (<i>n</i> = 5543, 82%)	<i>p</i> value for group differences *
Age in years	67 (SE .04, CI	70.7 (SE .026,	66.56 (SE .078, CI	< 0.001
(M, SE, CI, range)	67.2–67.4): 55–96	CI 70.2–71.2, 55–96)	66.4–66.72, 55–96)	
55–64 (<i>n</i> , %)	3222 (45%)	491 (31%)	2731 (49%)	
65–74 (<i>n</i> , %)	2282 (32%)	557 (35%)	1725 (31%)	
75–84 (<i>n</i> , %)	1222 (17%)	401 (25%)	821 (15%)	
85 (<i>n</i> , %)	403 (6%)	137 (9%)	266 (5%)	
Gender (<i>n</i> , %)				< 0.001
Male	3018 (43%)	707 (45%)	2311 (43%)	
Female	3981 (57%)	851 (55%)	3130 (57%)	
Race/ethnicity (<i>n</i> , %)				< 0.01
Non-Hispanic white	4360 (61%)	1108 (70%)	3252 (59%)	
Non-Hispanic Black	923 (13%)	135 (9%)	788 (14%)	
Hispanic	726 (10%)	107 (7%)	619 (11%)	
Other	343 (6%)	58 (4%)	285 (5%)	
Did not report	777 (10%)	178 (11%)	884 (16%)	
Education (<i>n</i> , %)				< 0.05
Less than high school	801 (11%)	165 (10%)	636 (12%)	
High school diploma	1720 (24%)	373 (24%)	1347 (24%)	
Some college	2168 (30%)	481 (30%)	1687 (30%)	
College grad or higher	2369 (33%)	554 (35%)	1815 (33%)	
BMI (M, SE, CI)	26.4 (SE .014, CI 26.1–26.7)	25.7 (SE 0.28, CI 25.2–26.3)	26.6 (SE 0.16, CI 26.3–26.9)	0.19
Smoking history (<i>n</i> , %)				0.16
Daily smoker	884 (12%)	149 (10%)	735 (13%)	
Occasional smoker	2473 (35%)	618 (40%)	1855 (34%)	
Never smoker	3666 (52%)	794 (50%)	2872 (52%)	
Internet user (<i>n</i> , %)				< 0.001
Yes	4519 (63%)	1016 (64%)	3503 (63%)	
No	2581 (37%)	565 (36%)	2016 (37%)	
General health (<i>n</i> , %)				< 0.001
Excellent/very good	2886 (42%)	581 (38%)	2305 (43%)	
Good	2673 (38%)	597 (38%)	2076 (38%)	
Fair/poor	1383 (20%)	365 (24%)	1018 (19%)	

* Calculated using svyset commands and adjusted Wald test

Table 2

Perceived importance of electronic health information access (weighted logistic regression)

Variable (compared to referent group)	Odds ratio	Std. error	p value	[95% conf. interval]
Gender (female)	1.01	0.14	NS	.76, 1.34
Age in years				
55–64	1			
65–74	0.62 **	0.11	< 0.01	.43, .89
75	0.34 **	0.07	< 0.001	.23, .50
Race/ethnicity				
Non-Hispanic white	1			
Non-Hispanic black	1.33	0.32	NS	.83, 2.12
Hispanic	0.96	0.85	NS	.62, 1.49
Other	0.67	0.21	NS	.36, 1.24
Education				
Less than high school	1			
High school diploma	1.17	0.25	NS	.78, 1.78
Some college	1.3	0.29	NS	.85, 2.00
College grad or higher	1.68 *	0.42	< 0.05	1.02, 2.76
Internet user (non-user)	0.32 **	0.05	< 0.001	.24, .42
General health				
Excellent/very good	1			
Good	0.91	0.13	NS	.70, 1.21
Fair/poor	1	0.19	NS	.69, 1.46
Ever had cancer (no cancer history)	0.99	0.15	NS	.74, 1.35

NS not significant

* $p < 0.05$

** $p < 0.001$

Table 3

Interest in at least one option for EHI exchange with providers (logistic regression)

Variable (compared to referent group)	Odds ratio	Std. error	p value	[95% conf. interval]
Gender (female)	0.93	0.07	NS	0.80, 1.08
Age				
55–64 years	1			
65–74 years	1.01	0.07	NS	(0.84, 1.01)
75 years	0.99	0.09	NS	(0.68, 1.07)
Race				
NH white	1			
NH black	1.51 **	0.17	$p < 0.001$	(1.20, 1.89)
Hispanic	1.5 **	0.21	$p < 0.001$	(1.14, 1.98)
NH other	0.88	0.17	NS	(0.6, 1.3)
Education				
Less than high school	1			
Completed high school	0.81	0.11	MS	(0.57, 1.16)
Some college	0.89	0.12	NS	(0.55, 1.27)
College grad or more	1.01	0.19	NS	(1.03, 1.7)
General health				
Excellent/very good	1			
Good	1.05	0.1	NS	(.88, 1.27)
Fair/poor	1.27	0.19	MS	(0.95, 1.69)
Smoking status				
Daily smoker	1			
Occasional smoker	1.29	0.21	NS	(0.98, 1.84)
Never smoker	1.54 *	0.17	$p < 0.05$	(1.01, 1.68)
Internet experience (non-user)	0.5 **	0.05	$p < 0.001$	(0.31, 0.47)
Ever had cancer (no cancer history)	1.01	0.09	NS	(0.84, 1.2)

MS marginally significant ($p < 0.10$),

NS not significant

*
 $p < 0.05$

**
 $p < 0.001$